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AUTHOR	Giliberti, Mary
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ABSTRACT

Children with serious emotional disturbance have the civil right to receive services in the most integrated setting appropriate to their needs. They further have the human right to be raised in their families and communities, with their individual needs guiding the service array provided. These civil and human rights are embodied in the Americans with Disabilities Act (ADA) and the values and principles of the System of Care. The Supreme Court held, in "Olmstead v. L.C.", that under the ADA, it is discrimination for a state needlessly to institutionalize an individual with a disability. This paper highlights the need for Olmstead efforts to address this discrimination by focusing specifically on children with serious emotional disturbances. It begins with a brief discussion of the Olmstead decision and principles to guide an Olmstead planning process. It then sets forth the values and principles of a System of Care. It outlines the current status of Olmstead planning for children before setting out some questions that must be answered in developing a comprehensive plan for children that is responsive to their civil and human rights. The document is designed to give some guidance to family advocates and state policymakers interested in statewide, systemic reform. It is hoped that they will use it to expand and guide their efforts to ensure that children are not left behind in the civil rights movement on behalf of individuals with disabilities. (GCP)

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MERGING SYSTEM OF CARE PRINCIPLES WITH CIVIL RIGHTS LAW

Olmstead Planning for Children with Serious Emotional Disturbance

Questions, Answers and Recommendations for State Policymakers and Advocates

Bazelon Center for Mental Health Law
November 2001

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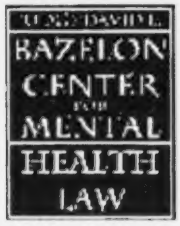

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The paper was written by Mary Giliberti, senior staff attorney at the Bazelon Center for Mental Health Law; it also benefited from review by Chris Koyanagi, the center's policy director, Trina Osher, policy director of the Federation of Families for Children's Mental Health, and Elizabeth Priaulx, community integration specialist at the National Association of Protection & Advocacy Systems.

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Olmstead Planning for Children with Serious Emotional Disturbance: Merging System of Care Principles with Civil Rights Law

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Olmstead Planning for Children with Serious Emotional Disturbance: Merging System of Care Principles with Civil Rights Law

Introduction

Children with serious emotional disturbance have the civil right to receive services in the most integrated setting appropriate to their needs.[1] They further have the human right to be raised in their families and communities, with their individual needs guiding the service array provided. These civil and human rights are embodied in the Americans with Disabilities Act (ADA) and the values and principles of the System of Care.[2]

The Supreme Court held, in *Olmstead v. L.C.*, that under the ADA, it is discrimination for a state needlessly to institutionalize an individual with a disability. The court specifically noted that one way states can show they are meeting their obligations under the ADA is to have a comprehensive, effectively working plan to serve people in the most integrated setting appropriate to their needs. Based on this suggestion, almost all states have begun Olmstead planning. Unfortunately, little effort has been made to include children with serious emotional disturbance in meaningful ways.

Unfortunately, in states' Olmstead planning, little effort has been made to include children with serious emotional disturbance in meaningful ways.

In addition to the ADA, the System of Care principles and values describe an appropriate children's mental health service system. The System of Care was developed in the 1980s to ensure appropriate services and supports for children with serious emotional disturbance, most of whom receive services from multiple agencies.[3] One of the principles calls for children to be served in the least restrictive setting that meets their needs. These principles have generally been accepted by the mental health professional community as the standard of practice for children's mental health care. Implementation, however, has lagged behind and generally been limited to select sites.

For many children, these rights and principles exist only on paper. To quote the Surgeon General's Conference Report on Children's Mental Health, "the nation is facing a public crisis in mental health care for infants, children and adolescents."[4] This neglect of children with severe mental health needs has tragic policy and personal consequences:

1) The emerging problem of "stuck kids"

In many states, children remain "stuck" in emergency rooms, hospitals and residential treatment facilities because intensive community-based

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"It is a national tragedy that American parents feel forced to have their children locked up simply in order to obtain desperately needed mental health services."
Paul Wellstone

services are unavailable or unaffordable. For example, a June 2000 *Boston Globe* article documented a growing problem in Massachusetts, where children are remaining in hospitals long after their discharge date because of a lack of alternatives. A Massachusetts State Senator quoted in the article said, "These kids aren't stuck. These kids are imprisoned and the Commonwealth is violating their civil rights."[5] The phenomenon is not limited to Massachusetts. Over the past five years, Yale-New Haven Hospital's emergency room in Connecticut has seen a nearly 60-percent increase in acute psychiatric cases. These children remain as "boarders" in the emergency room because appropriate placements and services are unavailable. A psychiatrist who presented the data at a conference received confirmation from her colleagues that this is, in her words, "a nationwide epidemic."[6] It is also extremely costly. A recent study from Nebraska concluded that the state could save $6.5 million if it efficiently moved children with mental health needs to appropriate less restrictive placements.[7]

2) Relinquishment of parental custody in order to access services

We have addressed this issue in great detail elsewhere, but it is unconscionable that in at least half the states, families are being told to give their children up to the child welfare system in order to access mental health care.[8] The National Alliance for the Mentally Ill (NAMI) reports that approximately one in five families of children with serious emotional disturbance were told to give up custody of their child to the state to get help.[9] With federal enactment of the Adoption and Safe Families Act, these parents risk losing their children permanently.[10]

3) Criminalization of children with serious emotional disturbance

The same NAMI report confirms that parents are also told to call the police and turn their children over to the juvenile justice system to get mental health care. Thirty-six percent of the families surveyed reported that their children were placed in juvenile justice because needed services were not available.[11] A Florida mental health advocate with the Broward Public Defender told *The Miami Herald* that "when law enforcement tells parents they have to have their kids arrested in order to access treatment, that unfortunately is the truth. The shameful truth."[12] In some states, children who are in acute need of psychiatric care are actually placed in facilities intended for juvenile offenders because no hospital psychiatric crisis bed is available.[13] "It is a national tragedy that American parents feel forced to have their children locked up simply in order to obtain desperately needed mental health services," says Paul Wellstone, the Democratic Senator from Minnesota. "This is a horrendous symptom of the discrimination against mentally ill children rampant in our health care system today."[14]

This paper highlights the need for Olmstead efforts to address this discrimination by focusing specifically on children with serious emotional disturbances. It begins with a brief discussion of the *Olmstead* decision and

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principles to guide an Olmstead planning process. It then sets forth the values and principles of a System of Care. It outlines the current status of Olmstead planning for children before setting out some questions that must be answered in developing a comprehensive plan for children that is responsive to their civil and human rights.

The document is designed to give some guidance to family advocates and state policymakers interested in statewide, systemic reform. It is our hope that they will use it to expand and guide their efforts to ensure that children are not left behind in the civil rights movement on behalf of individuals with disabilities.

Overview of the *Olmstead* Decision and the Principles of a Comprehensive Plan for Implementation

Two adult women with mental retardation and mental illness brought suit against the state of Georgia, claiming that they were being needlessly segregated in institutional settings in violation of the Americans with Disabilities Act. They prevailed in the lower courts and Georgia sought and was granted review by the United States Supreme Court.

The Supreme Court held first that "unjustified institutional isolation of persons with disabilities is a form of discrimination."[15] The court reached this conclusion based on two principles: 1) such institutional placement "perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life"; and 2) confinement in an institution "severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment."[16]

Although the *Olmstead* case involved two adult women, the reasoning is perhaps even more applicable to children. Needlessly segregating children contributes to the stigma and stereotype that they are bad children with bad parents who are not worthy of participating in their home communities. Placing children in institutions also cuts off their ability to participate in family outings, religious services, community activities, cultural enrichment and educational opportunities. Most important, needless confinement severely hampers family relationships, which are critical to mental health and development.

After finding that needless institutionalization is discrimination, the Supreme Court noted that states could defend against such a claim if they could show that providing services in a more integrated setting would be a fundamental alteration of the state's program.[17] In discussing fundamental alteration, the court recognized that states need some leeway to maintain the range of facilities needed and to administer services with an even hand. It stated that "if, for example, the State were to demonstrate that it had a comprehensive, effectively working plan for placing qualified persons with mental disabilities in less restrictive settings, and a waiting list that moved

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at a reasonable pace not controlled by the state's endeavors to keep its institutions fully populated, the reasonable modification standard would be met."[18]

The decision did not elaborate on the components of a "comprehensive, effectively working plan." However, the federal government has given states some guidance on that issue. In a letter to state Medicaid Directors dated January 14, 2000, the Center for Medicaid and State Operations within the then Health Care Financing Administration and the Office of Civil Rights provided some initial technical assistance recommendations on developing a plan.

Six principles are set forth in that document:

1) Develop and implement a comprehensive, effectively working plan (or plans) for providing services to eligible individuals with disabilities in more integrated, community-based settings.
2) Provide an opportunity for interested persons, including individuals with disabilities and their representatives, to be integral participants in plan development and follow-up.
3) Take steps to correct current and future unjustified institutionalization of individuals with disabilities.
4) Ensure the availability of community-integrated services.
5) Afford individuals with disabilities and their families the opportunity to make informed choices regarding how their needs can best be met in community or institutional settings.
6) Take steps to ensure that quality assurance, quality improvement and sound management support implementation of the plan.

System of Care Values and Principles

Olmstead planning represents an opportunity to incorporate System of Care values and principles into widespread reform efforts.

The values and principles of a System of Care (see box opposite) are similar to those needed for an effective plan, with additional emphasis on the unique relationship between children and families, the role of multiple agencies in addressing children's needs, the importance of early identification and intervention, and the need to plan for transitions from childhood to adulthood.[19] First elaborated in 1986, the System of Care is widely accepted in the literature and among mental health professionals as the guiding philosophy for providing mental health services for children with serious emotional disturbances.[20]

However, in practice, most systems of care have been created in select communities. For example, the Robert Woods Johnson Foundation, the Center for Mental Health Services within the Substance Abuse and Mental Health Administration, and the Anne E. Casey Foundation have each administered grant programs in specific sites. These extensive grant programs have yielded much information on best practices, but generally have not led to systemic or statewide reforms. Olmstead planning represents an opportunity to incorporate System of Care values and principles into widespread reform efforts.

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System of Care Values and Principles

Core Values:

1. The system of care should be child-centered and family-focused, with the needs of the child and family dictating the types and mix of services provided.
2. The system of care should be community-based, with the locus of service as well as the management and decision-making responsibility resting at the community level.
3. The system of care should be culturally competent, with agencies, programs and services that are responsive to the cultural, racial and ethnic differences of the populations they serve.

Guiding Principles:

1. Children with emotional disturbances should have access to a comprehensive array of services that address their physical, emotional, social and educational needs.
2. Children with emotional disturbances should receive individualized services in accordance with the unique needs and potentials of each child and guided by an individualized service plan.
3. Children with emotional disturbances should receive services within the least restrictive, most normative environment that is clinically appropriate.
4. The families and surrogate families of children with emotional disturbances should be full participants in all aspects of the planning and delivery of services.
5. Children with emotional disturbances should receive services that are integrated, with linkages between child-serving agencies and programs and mechanisms for planning, developing and coordinating services.
6. Children with emotional disturbances should be provided case management or similar mechanisms to ensure that multiple services are delivered in coordination and in a therapeutic manner and that the children can move through the system of services in accordance with their changing needs.
7. Early identification and intervention for children with emotional disturbances should be promoted by the system of care in order to enhance the likelihood of positive outcomes.
8. Children with emotional disturbances should be ensured smooth transitions to the adult service system as they reach maturity.
9. The rights of children with emotional disturbances should be protected, and effective advocacy efforts for children and adolescents with emotional disturbances should be promoted.
10. Children with emotional disturbances should receive services without regard to race, religion, national origin, sex, physical disability or other characteristics, and services should be sensitive and responsive to cultural differences and special needs.

The Current Status of Olmstead Planning for Children

According to the National Council of State Legislatures (NCSL), Olmstead planning is underway in some 40 states.[21] However, NCSL's report does not discuss planning for children's services. A review by the

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National Association of State Protection and Advocacy Systems (NAPAS) suggests that efforts on their behalf lag behind. NAPAS recently surveyed disability advocates[22] and found that out of 18 states[23] responding, only four[24] used a needs assessment specifically designed for children. Only three states[25] were including children soon to leave the school system in their planning efforts. Only three states[26] cover children in the foster care system and not a single state plan addresses the needs of children soon to leave detention or juvenile justice centers. Furthermore, only half of the states responding to the survey[27] indicated that children in residential treatment centers were specifically identified and addressed by the state plan.

NAPAS has collected state planning documents since the Olmstead decision. We reviewed those documents in preparation for this report and our findings confirm the survey. Very little attention is given to serving children in less restrictive settings, with few details and little recognition of the multiple agencies currently serving children with serious emotional disturbances. The few exceptions to this general rule are highlighted below as models for other states as they continue their planning efforts.

Some Questions to Ask About Olmstead Planning for Children

Combining the Olmstead and System of Care principles, we have devised a set of questions for state policymakers and advocates to consider when evaluating the adequacy of their state Olmstead plan for children with serious emotional disturbances.

1. Are youth with serious emotional disturbance, their families, and child advocates full participants in the Olmstead planning process?

Both the Olmstead and the System of Care principles call for full participation by youth and their families in all aspects of service delivery and planning, which should include system planning. Many of the state planning documents reviewed do not indicate the involvement of child and family advocacy groups in the Olmstead system-planning process. The University of South Maine, however, conducted focus groups of parents with children with special needs to better inform the Olmstead planning process in that state.[28]

Recommendation: States should make every effort to include representatives from family organizations such as the Federation of Families for Children's Mental Health and the local affiliates of NAMI's Child and Adolescent Network, as well as some youth or young adults themselves, who can give input into planning. Members of other child advocacy groups and individuals from a mental health advocacy organization, such as a chapter of the National Mental Health Association, who have a particular knowledge of and interest in children's issues should also be included in planning. To supplement actual participation by families and youth in the

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planning process, states should consider holding focus groups of families and youth to get information on the current barriers and strengths of the mental health service system for children with SED.

2. Does the plan identify the number of children in needlessly segregated settings or at risk of entry into these settings?

Both the Olmstead and the System of Care principles recognize that children should be served in the most integrated setting. The System of Care principles also note the multiagency involvement of many of these children. Accordingly, the plan should identify the number of children who are at risk of placement or currently placed in needlessly segregated settings by education, mental health, child welfare and juvenile justice agencies. It would be particularly useful to have estimates of the number of children who have been placed inappropriately in child welfare and juvenile justice because of mental health treatment needs and data on children who are in those systems appropriately but are currently placed in needlessly segregated settings. In reviewing state planning documents, we found no plans that included such an analysis and few plans that included data on the at-risk population or on children who are dually diagnosed (developmental disability and serous emotional disturbance or substance abuse and serious emotional disturbance).

States should make every effort to include representatives from family organizations in their Olmstead planning, along with some youth or young adults themselves.

Some states' plans do contain estimates of children in particular systems who were in restrictive settings. For example, Indiana had developed an Olmstead data-collection tool for all of its agencies. The Division of Mental Health completed the tool and included an attachment with a chart of children and adolescents in institutional care vs. community care.[29] In an Olmstead working document, Connecticut's Department of Children and Families noted that it served approximately 750 children and youth in residential settings as of April 2000, and approximately 20 percent (150) could be served in more integrated settings.[30] In the Working Plan for the State of Missouri, the Department of Mental Health noted that 76 children under 18 were currently in residential treatment and 49 were in non-institutional community-based residential settings, such as their natural home, independent apartments or supported living. Although the department did not indicate how many of the children in more restrictive settings could be placed in the community, it was asking for additional appropriations to fund community-based services for children with serious emotional disturbances and those dually diagnosed with both developmental disabilities and SED.[31]

Recommendation: Olmstead plans for children with SED should include data on the current number of children in each system (education, mental health, child welfare and juvenile justice) who are placed in restrictive settings and the number who could be served in more integrated placements. It should also include data on the number of children at risk of institutional placement and the number of children who have been inappro-

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priately placed in child welfare and juvenile justice because mental health treatment was not available. Finally, there should be a clear explanation of how the data were gathered.

Admittedly, it may be difficult to obtain accurate data because children are served by several systems, each with its own approach to record-keeping.It would therefore be necessary, in planning, to identify barriers to data collection and then explore ways to obtain the data needed for Olmstead implementation.

3. Does the plan describe an assessment process specifically designed for children and their families and for the purpose of ascertaining what is needed for the child to live in the community?

Olmsteaf plans should include data on the number of children at risk of institutional placement and the number who have been inappropriately placed in child welfare and juvenile justice because mental health treatment was not available.

The System of Care principles emphasize the importance of providing individualized services in accordance with the unique needs and potential of each child. Implementing *Olmstead* also requires a process for identifying individual strengths and needs. The assessment process for children with serious emotional disturbance has generally been problematic because of its exclusive focus on instruments that will calculate the degree of impairment, rather than ascertaining what is needed to serve a child in the most integrated setting.

The Surgeon General's report points out that "much of the mental health world operates from a deficit perspective, requiring families to prove their needs, rather than strengths, to get services."[32] There are a number of possible explanations for this, including the stigma of SED, the training of mental health providers, the negative circumstances associated with coming into contact with child welfare and juvenile justice, and the requirements to qualify for state-funded services and Medicaid services under options and waivers.[33] Generally, families must establish that children meet an institutional level of care, which has often been defined by looking at deficits.

According to a recent report by the National Institute of Mental Health (NIMH), another problem in assessment of children with SED is that "assessment of functioning has lagged behind assessment of clinical symptoms."[34] The report notes that functional assessments are particularly critical for children because symptoms are often complicated by the rapid developmental processes and do not fit into categorical classifications of mental disorders. Moreover, social, cultural, psychological and other factors influence children's experience and reporting of symptoms and current assessment processes does not capture this well.[35]

Few state planning documents discuss an assessment process for children. Those that do tend to use specific instruments, which should be analyzed to determine whether they adequately focus on strengths and determine what is needed to serve children with SED in the most integrated setting appropriate. Indiana is developing an assessment tool for children (HAPI-C), similar to the current tool used for adults, the HAPI-A, described as a "health related quality of life instrument for people with

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mental illnesses and addictions." The HAPI-C is designed to provide a level-of-functioning component and clinical-outcome data.[36] North Carolina's plan indicates that it will use the Child and Adolescent Level of Care Utilization System (CALOCUS), a standardized assessment protocol developed by the American Association of Community Psychiatrists, to assess first a 10-percent sample of residents of schools for children with serious emotional disturbance and state psychiatric institutions and then the entire population of these facilities. Importantly, the state intends to use a similar process for children at high risk of institutional placement.[37] Maine is using three assessment instruments: the CALOCUS, supplemented when appropriate by the Child and Adolescent Functional Assessment Scale (CAFAS) and the Behavioral and Emotional Rating Scale (BERS), used to measure emotional and behavioral strengths.[38] A report from South Carolina addresses the at-risk population by suggesting that Medicaid's Early and Periodic Screening, Diagnosis and Treatment program (EPSDT) should be expanded to include a more comprehensive behavioral assessment in the screening, to facilitate earlier identification of children with these disabilities and the early provision of appropriate services.[39]

The assessment process should focus on what is needed for a child to receive community-based services. Given the problems and paucity of tools, it would be very helpful if a federal agency provided resources for the development of guidelines specifically for a comprehensive Olmstead assessment process for children.

Recommendation: The assessment process should focus on what is needed for an individual child to receive community-based services. It is important to keep in mind that the Olmstead obligations are not synonymous with requirements for Medicaid and state funding. Moreover, to the extent that funding is relevant, states have much flexibility in determining the child's level of care and can use a balanced approach to achieve the objective of providing and funding community-based services.

Further analysis is needed to develop and circulate useful assessment processes for children with SED to determine what is required to serve them in the most integrated settings appropriate. Such assessments should include: 1) first and foremost, a focus on the child and family, emphasizing their strengths and an understanding of their cultural issues, through a process that values and centers on their input; 2) an evaluation of what would be required for the child to function at home, at school, with peers, in social activities, etc.; 4) age-appropriate questions; and 5) inclusion of any co-occurring issues, such as developmental disability or substance abuse.

The Office of Civil Rights at the Department of Health and Human Services (OCR) is developing some guidance on assessment parameters for all populations of people with disabilities. Given the problems and paucity of tools identified above, it would be very helpful if OCR or another federal agency, such as the Center for Mental Health Services, provided resources for the development of guidelines specifically for a comprehensive Olmstead assessment process for children with SED. These parameters should focus on information that should be gathered to determine how to serve the particular child in the community. To the extent that states prefer to use a specific assessment tool, one should be developed or recommended specifically for Olmstead implementation, i.e. determining what services

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and supports are needed to serve the child with SED in the most integrated setting. This effort can build on the current research analyzing and promoting strengths-based instruments for other purposes.[40]

4. Does the plan discuss treatment planning and offer children and families choices about services?

The Olmstead and System of Care principles indicate that families and children should be full participants in all aspects of planning for the services to be provided to them. The Surgeon General's Report notes the importance of "includ[ing] youth in treatment planning by offering them direct information, in developmentally appropriate ways, about treatment options. As much as possible, allow youth to make decisions and choices about preferred intervention strategies."[41]

Few state planning documents discuss treatment planning and options for children and families. Washington planning documents, however, indicate that youth who are involved in the child welfare system participate in service planning and sign the treatment plan.[42]

Indiana's planning document recognizes the importance of choice for families. Its plan has broken down existing geographic boundaries, added providers outside the mental health centers and allowed consumers to choose other providers.

As noted above, focus groups of parents of children with special needs, including mental health, were conducted in Maine as part of an Olmstead planning process. These focus groups stressed the importance of choice and indicated that parents were "very satisfied with programs that allowed them to hire in-home support staff, such as behavioral specialists or personal care attendants (PCA) for their children."[43]

The Maine focus groups also highlighted many problems with treatment planning that should be addressed in an Olmstead plan. Parents reported frustration with the fragmented service system. Families had to repeat information to various providers and agencies and wondered why the information was not better coordinated. Parents also had to use their informal networks to find the name of a provider who was reliable, and they learned "key phrases" to use when asking providers how to access services. The parents found that even health professionals were uninformed about most disabilities and many traveled out of state to get help because of the dearth of services. For example, Maine only has one pediatric neurologist.[44]

Indiana's planning document recognizes the importance of choice for families and the need to specify state activities to address this issue. The document notes that parents have almost no choice in institutional placements, which are geographically determined by region of residence. They also have had limited choice of community services because services were also allocated by geographic area, called catchment areas, and provided by a local community mental health center. Indiana has broken down these geographic boundaries, added providers outside the mental health centers and allowed consumers to choose other providers. The state is also taking specific action:

> To ensure that families are aware of the choice that they have available to them and to ensure that they have the information they need to participate in their own treat-

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> ment and recovery, the Division is entering into an agreement for Consumer Counseling services. This counselor will be responsible for providing information and choice to all consumers of community based services.[45]

Recommendation: Advocates and policymakers should evaluate the extent to which Olmstead plans specifically document the degree to which families and children (at age-appropriate levels) have adequate choice in providers and services. It is also important for the plan to address how families and children will have input in the treatment planning process itself (including accommodating language and other barriers to participation), and whether the treatment planning process is integrated across agencies. If there are deficits in any of these areas, the plan should include specific steps to remedy the problems.

5. Does the plan provide for transitions throughout childhood and between childhood and adulthood?

An NIMH report summarized this principle: "Childhood is characterized by change, transition, and reorganization; understanding the reciprocal influences between children and their environments throughout the developmental trajectory is critical."[46] The System of Care principles note the importance of ensuring smooth transition to the adult system.

Very few plans specifically address transitional issues. Indiana's planning document notes that the lack of specific services available for children transitioning into adulthood was one of the most significant barriers identified during the Olmstead needs-assessment process.[47]

An Illinois document discusses the requirements under the Individuals with Disabilities Education Act for transition planning in an IEP beginning at age 14.[48] It also recommends that the state fund and support increased transition-assistance programs so that "young people with disabilities and their families gain the knowledge and skills that they need to achieve a positive transition to the community."[49] Missouri's plan also cites the lack of involvement of schools in transition planning as a barrier; the plan recommends additional funding and a mandate for school districts to meet the requirements of the Olmstead decision.[50]

A South Carolina report discusses the need to strengthen transitional planning for children who are returning to the community to include family and natural support-system members and representatives from all agencies providing services, including education and vocational rehabilitation. The report notes the need to take into account the impact on the family of the child's return home and suggests that any plan should include resources to support the family in the transition.[51]

A South Carolina report discusses the need to strengthen transitional planning for children who are returning to the community to include family and natural support-system members and representatives from all agencies providing services, including education and vocational rehabilitation.

Recommendation: Advocates and policymakers should assess whether the Olmstead plan documents the extent of transition planning and services in all of the agencies that serve children, any barriers to transitioning and the

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specific steps to address the barriers or deficits. Transition planning should include all significant changes— i.e. preschool to kindergarten, grade school to middle, middle to high, developmental transitions, changes in placements and the transition to adulthood.

6. Does the plan discuss the development and funding of an adequate service array?

Several plans note the need for more of a particular service. Maine gives the number of children on wait lists for several services: case management, residential treatment, respite and recreational services.

According to a recent NIMH study, "the lack of availability and infrastructure support for treatments, prevention programs, and services is as high as it was in the early 1980s."[52] Both the Olmstead and the System of Care principles require a full array of available community-based mental health services needed to serve children appropriately. Accordingly, it is essential for Olmstead plans to evaluate the service array as well as the infrastructure support and financing issues.

None of the plans reviewed for this report undertakes a thorough analysis of the service array or gives concrete information and data on the availability of each service. Several note the need for more of a particular service, most often respite care for families.[53] Maine gives the number of children on wait lists for several services: case management, residential treatment, respite and recreational services.[54] A report from South Carolina notes shortages in a number of mental health services for children, including: behavioral support personnel trained in appropriate functional assessments; development of behavior support plans; training for staff and families as they implement the plans; counseling; and psychiatric services. The report also documents the lack of supports statewide to allow children to take part in social, recreational and vocational activities essential to their development, staff trained to assess, identify and work with children with co-occurring disorders, wraparound-service workers statewide, and trained school personnel to work with children with SED.[55]

Many of the plans that include children with serious emotional disturbance note the need for additional funding of community-based services for this population. Indiana's planning document states that lack of funding is the most significant barrier to Olmstead implementation.[56] Missouri notes that the Division of Mental Health has requested significant additional funding for services and supports to help families keep their children with SED at home and to expand the availability of treatment family homes in order to provide a home-like setting for children who must be removed from their own homes for a period of time.[57] Missouri's planning document also discusses a joint request for funding from the Division of Comprehensive Psychiatric Services and the Division of Mental Retardation and Developmental Disabilities (MRDD) to address the current lack of appropriate treatment alternatives for children who have developmental and mental health disorders.[58]

A few of the documents specifically address some of the funding sources for additional mental health services. Missouri's analysis states that it is considering the efficacy of a waiver for children with mental health and

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substance abuse needs.[59] It further notes that Missouri currently has a waiver to disregard parental income, but it is only utilized in the Division of MRDD and serves only 200 children. The state is considering exercising the TEFRA 134 option (also known as the Katie Beckett option), a Medicaid option that would allow the state to disregard parental income for any child with a disability and allow that child to live at home with appropriate Medicaid services.[60] The Maine focus groups noted the critical importance of the TEFRA 134 option for allowing children with inadequate private insurance to avoid institutionalization and get services in the community. One parent stated, "Katie Beckett coverage was a life-saver, without it my child would not have been able to get any counseling at all."[61]

Missouri is considering the use of waivers and options that would allow the state to disregard parental income for any child with a disability and thus enable that child to live at home with appropriate Medicaid services.

Recommendation: Advocates and state policymakers should review whether the Olmstead plans have a full discussion of the array of mental health services in the state and their availability throughout the state, particularly in rural areas.[62] The plan should note whether there are wait lists, either actual or in effect, and time lags in accessing services. It should address relevant workforce issues, such as the difficulties in finding and retaining behavior aides and respite workers.[63] It should also detail financing, including a consideration of all of the possible means for securing additional funds through waivers, options, parity laws and other methods.

7. Does the plan ensure that high quality services will be available?

The Olmstead and System of Care principles require that children receive services to address their needs appropriately. This includes effective services delivered in a culturally competent manner.

NIMH recently commissioned an exhaustive study to set forth a research agenda for children's mental health. The report analyzes all of the research findings on the efficacy of particular mental health treatments. It concludes that "most of the services available in most communities have no empirical evidence."[64] Yet the availability of effective interventions across the country is minimal.[65]

The report states that "treatments with strong evidence for youth with severe emotional disorders include multisystemic therapy,[66] intensive case management, and treatment foster care; for a number of other treatments (e.g. mentoring, family education and support), there is at least one randomized clinical trial.[67] Moreover, an important body of research is uncovering ineffective treatments. These include peer group-based interventions among high-risk adolescents, nonbehavioral psychotherapies, group homes and inpatient hospitalizations (improvements are not maintained after a child is returned to the community).[68]

The state planning documents reviewed do not specifically address the relative availability of effective and ineffective treatments. Nor do they discuss training of staff and providers to encourage use of effective treatments. Some plans, however, do indicate a need to increase treatment

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foster homes, one of the services found effective for children with SED.[69]

For services to be appropriate, they must be effective and culturally competent. The state planning documents generally do not assess the availability of culturally competent providers and services, including those who speak different languages or use sign language.

Recommendation: Although there is a need for further research measuring the effectiveness of particular treatments, Olmstead plans should reflect current knowledge. Plans should assess the availability of the most and least effective services and specify how resources will be adjusted to provide more of the effective services and less of the others. The plans should also address the availability of culturally competent services and steps that will be taken to develop them where needed.[70]

Plans should assess the availability of the most and least effective services and specify how resources will be adjusted to provide more of the effective services and less of the others.

8. Does the plan provide for quality improvement and data to track the outcomes that are important to children and families?

Olmstead principles state that quality assurance, quality improvement and sound management should support implementation of the state's plan. There is a critical shortage of data at the federal and state level that would allow for any analysis of progress under *Olmstead* in serving children in the most integrated setting. For example, there are no federal data on the number, percent and growth of residential vs. community-based services. The categories of Medicaid services that can be tracked are too general to allow for analysis of particular services such as residential treatment or behavioral health aides. Similarly, the state Olmstead planning documents did not track the number of children receiving institutional vs. community care, receiving particular types of treatment, and remaining on wait lists for services over time. This information will be critical to determine whether Olmstead planning is effective in achieving the goals of allowing more children to live in the most integrated setting appropriate to their needs.

A number of outcome indicators have been identified to assess the impact of the systems of care for children with SED and their families. These include the effect on: 1) out-of-home and out-of-community placements; 2) utilization of restrictive service options, including inpatient and residential treatment, and increased use of less restrictive placements and services; 3) youngsters' functioning; 4) educational status; 5) law enforcement status; 6) family involvement; 7) satisfaction with services; 8) access to services; and 9) costs.[71] The state planning documents reviewed did not adequately discuss or plan for measuring these or similar outcomes over time. Quality-assurance efforts discussed were often limited to licensing and accreditation and outcomes were often measured by performance on particular tests, such as the Child Behavioral Checklist (CBCL) or Child and Adolescent Functional Assessment Scale (CAFAS).

Recommendation: Olmstead plans should discuss quality assurance and outcome measures for ensuring that children are receiving services in the

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most integrated setting appropriate for their needs. Data should be compiled and reported in a way that allows both the state and all stakeholders to track progress in moving children to less restrictive settings and enabling them to achieve true community integration in school and at home, and outside of the criminal justice system.

9. Does the plan specifically address the challenges of multi-agency involvement in children's lives?

System of Care principles emphasize that children with SED should receive services that are integrated, with linkages between child-serving agencies and programs and mechanisms for planning, developing and coordinating services. Such linkages would reduce the incidence of children's being taken from their families and communities and entering child welfare and juvenile justice systems to get access to mental health services—services that, even in these systems, are usually in short supply.

There is little detail on interagency planning and development efforts in state planning documents. A few plans mention specific interagency initiatives to address service delivery, but do not give much information. For example, Arizona's draft Olmstead plan discusses a single joint purchase-of-care (SPOC) process, developed in collaboration between the Department of Economic Security, the Department of Juvenile Corrections and the Administrative Office of the Arizona Supreme Court to streamline the purchasing system of behavioral health care for children.[72] An Arkansas report of the Olmstead Working Group mentions Together We Can, an interdepartmental program that includes education, health and human services and integrates agencies based on local teams. Counties must choose to participate and, to date, 22 local teams are working to ensure that community-based services are available to children with behavioral health needs.[73] Iowa notes that it is holding a series of facilitated work groups to develop a cross-agency action plan to improve availability of and access to mental health services.[74] A South Carolina report suggests increased interagency coordination using existing programs, such as the Interagency System of Care for Emotionally Disturbed Children teams, to regularly staff children in institutional settings or at risk of placement into such settings.[75]

It is important for Olmstead plans to reflect the relationship between agencies and the fact that children seeking mental health services now often become part of a particular system as a matter of chance, not need.

Recommendation: Children with serious emotional disturbance have significant multi-system involvement. It is important for Olmstead plans to reflect the relationship between agencies and the fact that children seeking mental health services now often become part of a particular system as a matter of chance, not need. Juvenile justice and child welfare placements often remove children from their homes and communities, and Olmstead plans should assess the degree to which children are being placed in these systems because of the lack of mental health services. Because all children should be receiving an education, an Olmstead plan should also assess the coordination and availability of educational services with those provided by other agencies.

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Conclusion

Steven Hyman, Director of the National Institute of Mental Health, said it best when describing the state of children's mental health services:

> There is a terrifying gap between what we do know and how we act, between the services we could offer and those we do offer, and between what families can afford and what families can access.[76]

The Olmstead planning process provides a unique opportunity to address these gaps. Using the System of Care principles that have been developed and widely accepted in the children's mental health field and the Olmstead principles set forth by the federal government, stakeholders and states should create a plan for systemic change in children's mental health. Dr. Bernard Arons, Director of the Center for Mental Health Services, used the analogy of a surfer treading water in the ocean, waiting for the right wave to come along."That wave is here," he said, "particularly for children's mental health."[77] The Olmstead planning process can and should be the wave carrying children with serious emotional disturbances to shore. It is a matter of human and civil rights.

Notes

1. The Supreme Court stated that individuals have such a right unless the state can show that implementation would be a fundamental alteration. *Olmstead v. L.C.*, 119 S.Ct. 2176, 2188 (1999).
2. Children also have rights under the Individuals with Disabilities Education Act (IDEA), including the right to services in the least restrictive setting appropriate for the child.
3. Stroul, B. & Friedman, R. A System of Care for Children with Severe Emotional Disturbance (1986). The System of Care principles and values were developed for the Child and Adolescent Service System Program (CASSP), currently administered by the Center for Mental Health Services (CMHS) of the Substance Abuse and Mental Health Services Administration. Children's Mental Health: Creating Systems of Care in a Changing Society, Stroul, ed. (1996) at xxii.
4. *Report of the Surgeon Generals's Conference on Children's Mental Health* (2000) at 13.
5. Knox & Demner, "Trapped in a Mental Ward: State Lacks Programs for troubled youth," *The Boston Globe*, June 4, 2000 at A1.
6. *Id. The Washington Post* confirmed this by noting that at Johns Hopkins Hospital in Baltimore, visits to the ER by youngsters in psychiatric crisis have tripled and at Children's National Medical Center in Washington DC, admissions have doubled in the past year. Trafford, A. "Boarder Kids, on the Edge," *The Washington Post*, Health Section, June 27, 2000 at 25.
7. Larzelene, R., Chmelka, B. & Irvine, R. "Shrinking Treatment Capacity in Nebraska: Program, Treatment and Financial Implications." Presentation, October 5, 2001, Child & Family Coalition of Nebraska Conference.
8. Bazelon Center for Mental Health Law, *Relinquishing Custody: The Tragic Failure to Meet Children's Mental Heath Needs* (1999).
9. National Alliance for the Mentally Ill, "Families on the Brink" (1999) at 10.
10. This statute is designed to move children quickly to permanency and imposes

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very strict deadlines for considering whether to terminate parental rights. Although parents can argue that their child meets one of the statutory exceptions, the court makes the final decision.

11. *Id.*
12. Miller, "Parents: System Promised Help, Instead Delivers Harm," *The Miami Herald*, June 29, 2000 at 1A.
13. Knox & Demner, *Boston Globe*, June 4, 2000 at A1.
14. Cusak, "Arrest My Kid, He Needs Mental Health Care," *The Progressive*, 2001. http://www.progressive.org/amc0701.html
15. 119 S.Ct. at 2187.
16. *Id.*
17. 119 S.Ct. at 2188.
18. 119 S.Ct. at 2189.
19. Stroul, B. & Friedman, R. A. System of Care for Children and Youyh with Severe Emotional Disturbances (1986).
20. Stroul, B., Children's Mental Health: Creating Systems of Care in a Changing Society (1996) at 3.
21. National Conference of State Legislature, *The States' Response to the Olmstead Decision: A Status Report* (March 2001), indicating that 40 states have Olmstead task forces, of which several are opting to engage in activities to expand community-based services without developing a formal plan, and 14 states now have finalized plans or working drafts (available at www.ncsl.org/programs/health/Forum/olmsreport.htm). Updates to the report are expected in December 2001 or January 2002.
22. Priaulx, E., National Association of Protection and Advocacy Systems, *Olmstead Progess Report: Disability Advocates Assess State Implementation After Two Years*, at 12.
23. Alabama, Arizona, Arkansas, Florida, Georgia, Illinois, Indiana, Kentucky, Maryland, Massachusetts, Missouri, Montana, Ohio, Rhode Island, South Carolina, Texas, Washington and Wisconsin.
24. Indiana, Maryland, South Carolina and Wisconson.
25. Colorado, Indiana and Texas.
26. Indiana, Maryland and Wisconsin.
27. Alabama, Georgia, Indiana, Maryland, Missouri, Rhode Island, South Carolina, Texas, Washington and Wisconsin.
28. Ormond, Ziller & Richards, *Living In the Community:Voices of Maine Consumers*, Institute for Health Policy (2001). South Carolina's Department of Mental Health Workgroup also conducted focus groups around the state. South Carolina Home and Community-Based Services Task Force Report (Aug. 31, 2001) at 1-3.
29. Indiana Division of Mental Health, Olmstead Data Collection Tool, SED Children and Adolescents at Attachment V. North Dakota's Olmstead Work Group White Paper also details the number of children in out-of-home placement (1,720 unduplicated youth per year) and the percentage in residential treatment (35%) and family homes (65%). White Paper (November 6, 2000) at 9.
30. DSS Working Document, "Choices are for Everyone: Continuing the Movement Toward Community-Based Supports in Connecticut" (September 12, 2000) at 19. A working document from Washington State's Department of Social and Health Services Children's Administration indicates that 30-40 of the children in their care are ready to return to their own homes or community-based settings, are ready to enter foster care from an institution, or are at risk of institutionalization. Olmstead Planning Document at 6.

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31. Working Plan for the State of Missouri (December 29, 2000), Activity 1 at 7-8; Activities 6 and 7 at 40.
32. *Report of the Surgeon General's Conference on Children's Mental Health* (2000) at 33.
33. Caldwell, B., Lezak, A., MacBeth, G., & Newton-Logsdon, G., Overcoming Barriers to Serving Our Children in the Community: Making the Olmstead Decision Work for Children with Mental Health Needs and Their Families (draft of September 10, 2001) at 27.
34. The National Advisory Mental Health Council Workgroup on Child and Adolescent Mental Health Development and Deployment, "Blueprint for Change: Research on Child and Adolescent Mental Health" (2001) at 46. Hereinafter, "Blueprint for Change."
35. *Id.*
36. Indiana Division of Mental Health, Olmstead Data Collection Tool, SED Children and Adolescents at 12.
37. Serving Persons with Disabilities in Appropriate Settings: the North Carolina Plan (Dec. 28, 2000), Chapter 7 at 4 (defining children at risk as those with three or more institutionalizations in the past year, children with one or more admissions for more than two consecutive months in the past year, and children to have been accepted to state-run residential units but on the wait list.)
38. Maine's Plan Development Work Group for Community Based Living: DMHMRSAS: Children's Services (http:/community.muskie.usm.maine.edu/Materials/dmh_child.htm) at 4.
39. South Carolina Home and Community Based Services Task Force Report (Aug. 31, 2001) at IV-29.
40. See Early, T.J. (2001) Measures for practice with families from a strengths perspective. *Families in Society: The Journal of Contemporary Human Services*, 82(3), 225-232; Graybeal, C. (2001). Strengths-based social work assessment: Transforming the dominant paradigm. *Families in Society: The Journal of Contemporary Human Services*, 8(3), 233-242; Epstein, M.H. (1999). The development and validation of a scale to assess the emotional and behavioral strengths of children and adolescents. *Remedial and Special Education*, 20 (5), 258-262; Lyons, J.S., et al., Stengths of children and adolescents in residential settings: Prevalence and associations with psychopathology and discharge placement. *Journal of the American Academy of Child and Adolescent Psychiatry*, 39(2), 176-181. See also Canino G., Costello, J.E., & Angold A., (1999). Assessing Functional Impairment and Social Adaptation for Child Mental Health Services Research: A Review of Measures. Mental Health Services Research (12) at 93-108.
41. *Report of the Surgeon General's Conference on Children's Mental Health* (2000) at 9.
42. Washington Department of Social and Health Services, Children's Administration, Olmstead Planning document at 2.
43. Ormond, Ziller & Richards, *Living In the Community: Voices of Maine Consumers*, Institute for Health Policy (2001) at 29.
44. *Id.* at 32-34.
45. Indiana Division of Mental Health, Olmstead Data Collection Tool, SED Children and Adolescents at 11.
46. "Blueprint for Change" at 4.
47. Indiana Division of Mental Health, Olmstead Data Collection Tool, SED Children and Adolescents at 13.
48. Report on Illinois' Activity in Response to the Americans with Disabilities Act in Light of the *Olmstead* Decision, Steering Committee of HR 0765 (December 20, 2000) at 23.

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49. *Id.* at 24.
50. Working Plan for the State of Missouri (December 29, 2000), Activity 8 at 12.
51. South Carolina Home and Community Based Services Task Force Report (Aug. 31, 2001) at IV-28.
52. "Blueprint for Change," at 21.
53. Living In the Community: Voices of Maine Consumers (July 2000) at 30 (noting wait lists of approximately five months for respite services); South Carolina Home and Community Based Services Task Force Report (Aug. 31, 2001) at III-21 (noting that respite is the need most frequently cited by families with disabilities and stating that barriers to additional respite services include insufficient capacity, both in terms of trained providers and money to pay them, and federal prohibitions on using Medicaid to pay family members for respite).
54. Maine's Plan Development Workgroup for Community Based Living: DMHMRSAS: Children's Services (http:/community.muskie.usm.maine.edu/materials/dmh_child.htm) at 5.
55. South Carolina Home and Community Based Services Task Force Report (Aug. 31, 2001) at III-19.
56. Indiana Division of Mental Health, Olmstead Data Collection Tool, SED Children and Adolescents at 13.
57. Working Plan for the State of Missouri (December 29, 2000), Activities 6 and 7 at 40. Texas' plan also notes the need for a community based model through which children in crisis can be placed out of home, but not be required to enter the foster care system. Such a program "allows families to make decisions regarding alternative family options for their child without the stigma associated with CPS, which presumes abuse and neglect." Texas Promoting Independence Plan (January 2001) at App. D.
58. Working Plan for the State of Missouri (December 29, 2000), Activities 6 and 7 at 40.
59. Working Plan for the State of Missouri (December 29, 2000), Activity 6 and 7 at 29. South Carolina's Home and Community Based Services Task Force Report also notes that children in the mental health system do not qualify for the state's existing waiver programs. Task Force Report (August 31, 2001)at III-22.
60. Working Plan for the State of Missouri (December 29, 2000), Activity 6 and 7 at 29-31, 35.
61. Ormond, Ziller & Richards, 2001, at 74.
62. See Bazelon Center for Mental Health Law, *Making Sense of Medicaid*, (1999) for discussion of the full array of services that can be funded under Medicaid.
63. South Carolina's Home and Community Based Task Force Report includes some recommendations for direct care and in-home care workers recruitment, retention and training. Task Force Report (Aug. 31, 2001) at IV-32.
64. "Blueprint for Change" at 67, citing English (in press).
65. *Id.*
66. *Id.* at 69 defines multisystemic therapy (MST) in detail. MST involves working with the child and family in the child's environment to create conditions in which antisocial behavior will be reduced and presocial behavior increased. The therapist's time is spent in the settings where the child and family are; the therapists do not have or use private offices.
67. *Id.* at 68.
68. *Id.* at 67. See also, *Mental Health: A Report of the Surgeon General* (1999) at 171 ("given the limitations of current research, it's premature to endorse the effectiveness of residential treatment for adolescents").

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69. Working Plan for the State of Missouri (December 29, 2000), Activities 6 and 7 at 40; Texas Promoting Independence Plan (January 2001) at App. D.
70. For a detailed discussion of cultural competence and a list of major cultural competence principles, see Isaacs-Shockley, et al., "Framework for a Culturally Competent System of Care," in *Children's Mental Health: Creating Systems of Care in a Changing Society* (1996) at 23-37.
71. Stroul, McCormack and Zaro, "Measuring Outcomes in Systems of Care" in Stroul, B., *Children's Mental Health: Creating Systems of Care in a Changing Society* (1996) at 319-320.
72. Arizona Draft Olmstead Plan (June 2001) at 30.
73. Report of the Olmstead Working Group (February 2001) at xxvii.
74. The Iowa Olmstead Report (August 31, 2000) at 3.
75. South Carolina Home and Community Based Services Task Force Report (Aug. 21, 2001) at IV-40.
76. *Report of the Surgeon General's Conference on Children's Mental Health* (2000) at 18.
77. *Id.* at 19.

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